ANONYMOUS
Witness Name: GRO-B
Statement No: WITN5374001
Exhibits: WITN5374002 - WITN5374004
Dated: 26 May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 March 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1958. I reside in Oxfordshire, and my full address is known to the Inquiry. I married my husband GRO-B: H in 1978, and we do not have children. I am currently in full-time employment, as both a stores clerk for a medical company and in Environment Health Safety.

2. I have one sister, one older brother and one younger brother who died in GRO-B 2001, three months before my husband's death in GRO-B 2002.

3. I intend to speak about my husband's infection with Hepatitis C (HCV), after having received contaminated blood product as treatment for his haemophilia. In particular, the nature of how we had learnt about his infection, how his illness had affected him, and the impact it had on our lives thereafter. H 's date of birth is GRO-B 1959, and his date of death was GRO-B 2002.

4. I can confirm that I am not currently legally represented and have chosen not to have legal representation and that I am happy for the Inquiry team to assist with my statement. The Inquiry Investigator has explained the anonymity process to me and I wish to be anonymous as I am talking about sensitive and personal details.

5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

7. I have constructed this statement without access to H 's medical records.

Section 2. How Affected

8. H and I were childhood sweethearts. We had known each other fromaround the age of five years old, and we went through both primary and secondary school together. Whilst we had a few years apart, we got back in touch with one another, and in 1978 at the age of nineteen, we got married and bought our first house together.

9. H had always loved football and cars. He was a mechanics apprentice at GRO-B when we got married and he later became a mechanic as a tradesperson. He had always wanted to play football as he loved the game, so he would play for the local team on the weekends. He played football through school and then went on to play for the local football team.

10. However, as H had Haemophilia B (which is more commonly known as "Christmas Disease"), this had an effect on his ability to play football as often as he would have otherwise liked.

11. Whenever H suffered a knock or a bleed, he would receive treatment at the GRO-B Hospital, ("GRO-B"), GRO-B. He would visit the GRO-B on a regular basis for treatment under the care of Doctor Giangrande and Sister Raw. Sometimes this was on a weekly basis, and other times, he would go a few weeks without visiting the hospital.

12. H tried to lead as much of a normal life as possible with his haemophilia. However, as he became older, he was always in and out of hospital for treatment. In the end, due to the strain his injuries were causing on his body, he had to give-up playing football.

13. To my knowledge, H was diagnosed with Haemophilia B when he was aged two years old, following an appendectomy to remove his appendix. As confirmed on his Special Medical Card dated 01 January 1965, entitled Haemorrhagic States and issued by the Health Departments of the UK (Exhibited at **WITN5374002**), he had 8% Factor IX. He received regular treatment of Tranexamic Acid and Factor IX blood product for his haemophilia.

14. In the late 1980s, H developed a ganglion cyst on his hand and because of the nature of his work he kept knocking which was a risk factor. Not long after, he underwent an operation to have it removed at GRO-B Hospital. During the surgery, he received Factor IX.

15. From this point on following H's operation, I began to notice that both his physical and mental health had started to go downhill. He was always mentioning that he felt constantly tired, and that he was down in his mood. I thought this was very odd and out of the ordinary for H as he was ordinarily a very happy and out-going man.

16. Thereafter, H's health continued to decline over a long period of time, and as a result, he turned to alcohol as a coping mechanism. It was very much a vicious cycle as the worse his health had become, the more he drank. However, in turn, his persistent drinking meant that he experienced even further problems with regards to his health.

17. In the late 1990s, we noticed that his stomach had become enlarged beyond normal size, so we sought medical assistance from our local General Practitioner ("GP") Doctor GRO-B at the GRO-B GRO-B. After initial observations, Doctor GRO-B referred GRO-B for further tests with the Liver Specialist at the John Radcliffe Hospital ("John Radcliffe"), Headley Way, Headington, Oxford, OX3 9DU.

18. Due to H's diminishing health, I began to drive him to his medical appointments at the John Radcliffe. I then started to attend a number of his appointments with him during the last 5 years of his life.

19. On one occasion I can recall attending a face to face consultation with H to visit the liver specialist; Jane Collier. During the conversation, it was mentioned that H's drinking had exacerbated the damage originally caused to his liver by his HCV.

20. I immediately thought to myself, HCV? This was the first time HCV had ever been mentioned by the medical professionals in my presence and I was in complete shock.

21. Was this the first time H had ever been told about his HCV diagnosis? Had he been diagnosed with HCV before this point? I do not know. I am very much in the dark about his HCV diagnosis as to the timeline.

22. To my knowledge, H had not received anything in writing that confirmed he had been infected with HCV. He may have been told about this during an appointment with his liver specialist in the past, however, I cannot confirm this as fact. If he had, then I was not made aware of this either by the medical professionals or H. There has always been this grey area surrounding whether H was aware of his HCV beforehand and when he first became aware.

23. As his wife I would have assumed that H would have told me about his HCV infection as we were so close. We had been married for a number of years at this point. However, as he was a very private person, he may have wanted to keep it to himself and deal with it on his own without worrying me. Again, I cannot state this as fact.

24. Looking back, I cannot say for certain at what point H had become infected with HCV. In hindsight, through a process of elimination, it is now my belief that he may have become infected as a result of the operation he had undergone at GRO-B Hospital in the late 1980s to remove his ganglion; as referred to in **Section 2, Paragraph 14** of my statement.

25. During the aforementioned operation, he received Factor IX as treatment. It is therefore likely that this blood product was contaminated with the presence of HCV, and was the cause of his infection. However, this has not been confirmed as fact.

26. I have a document dated 22 July 1997, from Dr M Moosang, Senior House Officer to Dr Giangrande, GRO-B, addressed to Dr GRO-B, GRO-B (Exhibited below, **WITN5374003)** which states:

> "*Diagnosis:*
>
> 1. *Mild haemophilia B (Baseline factor IX level 8%)*
> 2. *HCV Positive, PCR positive*."

27. This letter would suggest that the medical profession had become aware that H had contracted HCV prior to 1997. This would fit into the time line of my belief in which he had contracted HCV during an operation in the late 1980s.

28. I wish H's HCV infection had been mentioned by the medical profession at an earlier point in time. I cannot say for certain at what point he had been PCR tested, or at what point they had become aware of his infection, but, it is my understanding that they may have known for some length of time before I had become aware.

29. If I had become aware of H's HCV at an earlier point in time, or I had otherwise been given full and adequate information on how I could manage and understand his infection, it would have allowed me to put in place prevention measures to prevent any risk of infection to others and to safeguard my own health.

30. I believe that as his wife, I should have been notified of this information. It was never fully explained to me that there was a risk to others being infected as a result of his HCV. With H's drinking there were a number of occasions where he would fall over and on one occasion he cut his head badly. Due to his haemophilia this meant that he would often bleed profusely, and I would clear up his blood not otherwise aware of the potential risks of infection.

31. When I used to touch H's blood, he would not ever interfere or tell me otherwise not to do so. Therefore, I do not believe that he had been provided with adequate information on how to manage and understand his HCV. If he had otherwise understood the severity of any contact with his blood, due to H's kind nature, he would have ensured that I would not have put myself at risk.

32. From between the late 1990s and 2002, H spent a lot of time in bed at our home. This was partly as a result of both his drink and his low mental health.

33. On the night of Friday 15 February 2002, H asked me to help him out of bed. However, as soon as he stepped out of bed he collapsed. I immediately knew that he was not in a good way with regards to his health so I telephoned for an ambulance immediately.

34. Once the ambulance arrived at our home, the paramedics worked to stabilise him before transporting him to the John Radcliffe for medical assistance. I sought separate transport to the hospital.

35. As soon as I arrived at the John Radcliffe, I was told that he had been placed in the Resuscitation Unit. I asked the medical staff on duty why he had been taken there, to which they had told me he was very sick. I immediately knew that this was bad news.

36. After a short while, I was permitted to go into the Resuscitation Unit with him. I can recall being greeted by a number of doctors and nurses flying around the room in an attempt to provide medical assistance to H. Whilst I was there H suffered a massive haemorrhage, it was horrific as there was blood everywhere. After a while, they asked me to step outside the room so that they could work on him.

37. It was all so sudden, and out of the blue. I had no warning of what could happen and I was not prepared for it. Sadly, on GRO-B 2002 H passed away whilst at hospital.

38. They told me that he had suffered a massive haemorrhage. Upon inspection of H's death certificate, I became aware that Hepatitis C disease was also listed as a cause of death. His death certificate states (Exhibit **WITN5374004)**:

> *"I (a) Massive Oesophageal Bleed*
> *(b) Hepatitis C Disease*

> *II Christmas Disease”*

39. I didn’t experience any issues with regards to the funeral directors for H’s funeral. They were friends of H and I so they were fantastic and very good to me. H’s HCV diagnosis did not cause any issues as it was not, and still is not commonly known.

40. At my request, I asked the guests at H’s funeral to provide a donation to the Haemophilia Centre at GRO-B. They did so much for him with regards to providing treatment for H’s haemophilia, and I wanted to give something back, however small.

Section 3. Other Infections:

41. I do not believe that H had received any infection or infections other than HCV as a result of being treated with contaminated blood product.

42. A letter dated 22 July 1997, from Dr M Moosang, Senior House Officer for Dr Giangrande, GRO-B, to Dr GRO-B GRO-B (Exhibit **WITN5374003)** states:

> “H *remains adequately immunised against hepatitis B and is still hepatitis C positive and HIV negative*.”

43. This letter demonstrates that whilst he had been tested for the presence of HIV, it had returned a negative result but records that he was, “still hepatitis C positive.”

Section 4. Consent

44. Whilst H had received treatment for his haemophilia from an early age, I believe that his parents would have provided consent on his behalf until he passed the age of consent at eighteen years old. Beyond this point, I believe that H would have provided consent for his treatment thereafter.

45. I do not believe that H was ever treated without his knowledge or having been given adequate information, apart from clearly not being given adequate information as to how to manage his HCV infection, as previously stated. In addition, I am not aware that he had been tested or treated for the purposes of research. He was simply treated as and when he was in need of treatment due to his bleeds. However, if he had, then I was not made aware of this fact.

Section 5. Impact.

Mental/Physical Effect

46. In the lead up to H's death in 2002, his physical and mental state had deteriorated. In hindsight, I attribute this to his HCV infection. As far as I have knowledge, I firmly believe that H contracted HCV as a result of contaminated blood product he had received during an operation in the late 1980s to remove a ganglion cyst on his hand or before because of the Factor IV he received for the treatment of his haemophilia. Ever since this point, he was no longer my H. His body suffered both physically and mentally. Therefore, I believe that all of his health concerns are owing to his HCV.

47. Approximately ten years into our marriage, and after his operation in the late 1980s, H began to complain of persistent fatigue and tiredness. Prior to this, he was always active and continually carrying out activities such as fixing cars. His fatigue meant that he was no longer able to go about his usual day, and in part, spent large lengths of time in bed resting.

48. H also developed an enlarged and distended stomach which was protruding in nature. After seeking medical assistance from both his GP and the GRO-B GRO-B, it was explained to us that it was a sign of the damage that his HCV infection had caused to his liver.

49. His general feeling of malaise had a direct effect on his mental health. He was no longer the H I once married. He was always at a very low ebb and life and his whole health situation was difficult for him to deal with. It was as if his personality had completely changed and I was living with a different person. I did not recognise him anymore and it was difficult to watch.

50. As a coping mechanism H turned to alcohol. As his health got worse, so did his drinking. It was a vicious cycle which also further exacerbated the existing damage to his liver.

51. Both H and I tried to access help from our local GP not only for himself, but for both of us. He was advised to give up the drink for his health, but as it was his way of getting through the pain this did not materialise, although he tried numerous times. He was referred by his GP to Alcoholics Anonymous ("AA") for assistance, for which he held a membership for a short period of time. I was also able to get him a place at a Rehabilitation Centre, which I paid for, but he only stayed there for a short while.

52. In the end, H always turned back to alcohol. He really did try to get help and to abandon the drink, but it was his way of shutting things out mentally. He would refer to it as his prop or coping mechanism.

Treatment

53. To my knowledge I do not believe that H was offered any treatment for his HCV. Furthermore, the letter dated 22 July 1997 from Dr Moosang to GRO-B's GP, as mentioned in paragraph 26 above, also states that H's HCV infection was still prevalent at that time. Whilst he was given treatment to administer

himself at home in the form of tranexamic acid, this was for his haemophilia not his HCV.

Impact

54. When I married H in 1978, he told me that he did not want to have children as he did not wish to pass on his haemophilia. He knew the impact it would have on their lives, and he did not wish that on anyone, let alone his family. I understood his wishes. I loved him for who he was and I accepted this.

55. It was very hard for me to cope with the effects his haemophilia had on his body, but in addition to his alcoholism and his HCV this was difficult. He used to describe his health as a ticking time bomb waiting to go off in his head with regards to how his body and mental health felt and he used to say that he wouldn't make 'old bones'.

56. After his death in GRO-B 2002, I was placed on anti-depressants by my GP. This was in part an aid to help me sleep, and I only took them for a short period of time.

57. Growing up, H loved football and dreamt of becoming a professional football player in the future, as he had the potential to do so. However, due to the effects his haemophilia had on his body, he was not able to make this into his profession; despite having the talent.

58. He also had a passion for cars. He was a very clever man and took extended training courses in Heavy Goods Vehicles ("HGV"). He was able to gain an HGV license as a result. In the end, H became a mechanic by trade. He began working for GRO-B. He later set up a mechanic company with his friend who he worked with and they took on GRO-B and renamed it, and that was a great success.

59. However, after H's health had taken a turn for the worst, so did his business. The effects of his mental health and alcoholism meant he was unable to go to

work most days, so the relationship with his business partner deteriorated. After a while, the company shut down and H was always at home. He did not work again after this point.

60. The responsibility fell on my shoulders to become the sole breadwinner for H and I, so I worked full-time to keep things ticking along. It was always a struggle. I worried that I did not have the ability to cope but I did not let it defeat me. We were living in our dream home in the village we had always wanted to live in, so I did all I could to keep our house.

61. To this day I work full-time to make ends meet. H's HCV diagnosis and subsequent death has had a huge financial impact on me. After H's death, my mother moved into our home to stay with me until the funeral for a period of around six weeks. During this period, I was unable to work and was signed off for 6 weeks. Without his death, it would have been a different story. It was not something I had foreseen.

62. I live in a very small village. Only my friends know that H was a haemophiliac and that he had an alcohol problem in his later life. No one knows that he had HCV. In our family, HCV was not something we discussed. Similar to my friends, they knew he was a haemophiliac but his infection was not spoken about.

63. As we kept the information surrounding his HCV infection very close to our chests, his infected status did not have an impact on his private, family, or social life in terms of stigma.

64. We had not experienced any issues with regards to stigma associated with HCV, as no one knew. Around the time I had found out about his HCV, information about HIV was published on the news. An association with haemophilia was also mentioned; so, I was surprised that no-one had questioned H's health. If people had become aware, then this may have been a different story.

Section 6. Treatment/Care/Support

65. The medical professionals at the GRO-B Haemophilia Centre were always very good with providing adequate treatment, care, and support to H for his haemophilia. They were always there for him so I cannot fault them for what they did for H. I cannot say that at any point they did not care for him.

66. However, in comparison, this was almost the opposite with regards to the health care he was provided with for his HCV. It was always very vague. It is my belief that they did not manage his infection very well. Whilst he visited the GRO-B regularly for routine treatment and check-ups, I cannot distinguish whether this was for his haemophilia, HCV, or both. I do not know this as a fact. Therefore, as I did not know the full extent of the treatment care and support he received for his HCV; as I was always left in the dark, I cannot say that he faced any difficulties or obstacles in obtaining the aforementioned.

67. If H had received adequate enough treatment, care and support for his HCV infection, surely, I would have been made aware? In hindsight, it would have been nicer to have more of an understanding of what was going on than not knowing at all. A better understanding might have helped matters.

68. To my knowledge, H's infected status did not have an impact on the dental care he received. He was not ever refused any regular dental treatment, and if he needed to undergo a more extensive procedure, he would visit the GRO-B because of the risks of bleeding associated with his haemophilia.

69. I do not believe that H was offered any counselling or psychological support as a result of his HCV diagnosis. Whilst the GP offered counselling through the AA, this was for his alcoholism and not his HCV.

70. I was not offered any counselling as a result of his HCV diagnosis. I was however provided with counselling as a result of his death through my GP. This

was provided through the National Health Service ("NHS"). It is my belief that I should have been offered counselling prior to his death. I was going through a very difficult period of time trying to cope with the effects his infection had on his body, so it would have been beneficial.

71. After H's death in 2002, I contacted my GP to ask whether I could be tested for HCV. I wanted peace of mind for myself and others. My thoughts were that if I had tested positive, I would need to manage my health. I would also be in a position to adequately understand how to manage my infection and reduce the risk of infecting others as a result.

72. Sometime after H's death, I attended a face to face consultation with my GP, I was later tested for HCV by a nurse at the surgery. Not long after, the test result showed that I had tested negative for the presence of HCV.

73. Whilst H was still alive, testing was not mentioned by any medical professional. It was only as a result of presenting myself to my GP to ask for a test, that I was provided with the opportunity.

Section 7. Financial Assistance

74. Prior to March 2011, I had not been made aware of the financial assistance offered by the Skipton Fund for both infected and affected persons associated with HCV. It was only as a result of the secretary, Sharon, at the GRO-B Haemophilia Centre who contacted me via telephone in March 2011, that was I was made aware. Sharon had notified me that I could possibly apply for financial assistance from the Skipton Fund as an affected person relating to H's HCV.

75. Therefore, in March 2011, I took the advice of the Haemophilia Society, and sent an application form to the Skipton Fund to seek financial assistance.

76. From my perspective, I did not find the process of applying to the Skipton Fund a painful procedure. I simply filled out the forms they sent to my address with the relevant information, then Dr Giagrande confirmed and signed the forms. Then, if I qualified, they would contact me to let me know the outcome.

77. On 14 April 2011, I was notified by the Skipton Fund that my application had been successful and that they would be making a Stage One ex-gratia payment in due course.

78. On 06 May 2011, I was paid a Stage One ex-gratia payment of £20,000 as a lump sum. Thereafter, I have not received any further payment(s).

79. From my understanding, I am unable to apply for a Stage Two payment as I believe that this is only available to persons who had developed liver cirrhosis as a result of their HCV infection and it is not clear if H had gone on to develop cirrhosis. However, he was under the care of a liver specialist having been referred by his GP due to problems with his liver including his distended stomach.

80. I do not believe that I experienced any difficulties or obstacles in applying for and or obtaining the initial financial assistance from Skipton. In addition, there were not any preconditions imposed on the making of the application or granting of financial assistance.

81. In hindsight, £20,000 does not appear to come anywhere close to trying to compensate the loss I experienced as a result of the death of my husband. It has not ever been about the money for me, but this sum appears to be the price they have placed on his life.

82. Without the kindness of Sharon at the GRO-B Haemophilia Centre in contacting me, I would not have known about the existence of the financial assistance available from the Skipton Fund. No medical professional had ever mentioned it prior to this point.

Section 8. Other Issues

83. Before being contacted by a representative from the Infected Blood Inquiry, I had not been involved in any previous Inquiry or group litigation.

84. I am providing a witness statement to the Infected Blood Inquiry as I wish to help other people who are still alive and are going through a similar process that I went through with my husband.

85. If there was anything that could be achieved as a result of the work of the Infected Blood Inquiry, it is to provide a greater understanding of how HCV impacts on peoples' lives. We were unaware of the enormity of the effects his HCV would have, both physically and financially. Not only on H's life, but my own. It was the not knowing that had the largest impact. If it had been discussed with us from the outset, it would have helped us to prepare for what was to come. I hope that raising awareness of my story will help people in a similar situation to ours, to be better prepared for the future.

86. Comparatively, with the presence of coronavirus having been with society for over a year at the point of making my statement, I note that there has always been information available to the public regarding Covid-19, as well as support, and preventative provisions to take to prevent the spread of infection to others. It has been tragic for so many families, and I only wish that I could have been given the same amount of information when H had been diagnosis with HCV.

87. H was a very talented person. I still hold on to his certificates of achievement as a memory of what an incredible man he was. It was such a waste of a life that he died young. We were married for twenty-four years when he died and left our dream home we made together. If he had not been given contaminated blood product as treatment, our lives could have been so different. Who knows what life could have otherwise had in store for us?

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-B

Dated 26 MAY 21

Table of Exhibits:

Date	Notes/ Description	Exhibit number
01 January 1965	Special Medical Card, Haemorrhagic States, Health Departments of the UK.	**WITN5374002**
22 July 1997	Letter from Dr M Moosang, Senior House Officer to Dr Giangrande, GRO-B GRO-B, to Dr GRO-B GRO-B.	**WITN5374003**
18 February 2002	Death Certificate of H, certified by Anne Cassidy, Registrar for the County of Oxfordshire.	**WITN5374004**